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Chapter 1

General Introduction

Ik
schrijf gedichten
als dunne bomen

Wie
kan zo mager
praten
met de taal
als ik?

Misschien
is mijn vader
gierig geweest
met het zaad.

Ik heb
Hem nooit gekend
Die man.

Ik heb
Nooit een echt woord gehoord
Of het deed pijn.

Om pijn
Te schrijven
Heb je
Weinig woorden
Nodig.

Jan Arends (1974)

I
Write poems
As thin trees

Who
can talk
as sober
with words
as I do?

Maybe
my father
has been mean
with the semen

I have
never known him
that man.

I have
never heard a true word
that did not hurt

To write
pain
you need
few words

This poem gives a very powerful image of the existential experience of suffering from a mental illness. The author lived a tormented life with depressions, anxiety and alcohol addiction until he committed suicide in 1975 at the age of 48. The poem conveys a strong image: leafless bare trees, that stand for pain and the inability to communicate with language. The poet needs few words because he deploys a visual image that makes his message clear almost at an instant. The poem itself also has a long stretched out format that reminds of thin trees. It illustrates the power of images where words alone fail to express what we mean. It makes us aware that suffering from mental illnesses is always an embodied and lived experience that translates itself into sensory and imaginary meanings that stand out as symbolizations for actual situations. Jan Arends experienced loneliness because he was not able to communicate with others who often shunned contact when they recognized in him the stigma of mental illness. The pain caused by this experience was symbolized in the poem in what is almost a photograph: thin trees pointing into the sky, accusative to heaven of his fate.

Images often play an important role in poetry. However, only few patients suffering from mental health disorders have the same skills as Jan Arends to conjure up powerful images in a poem. Fortunately, there is an easier way to share their images with others. Patients can make photographs and talk about them. We developed a tool, called the photo-instrument, for nurses to assist patients in making photographs of their life world in a structured way and talk about the meaning of what they photographed. In making photographs, patients do not need words to picture aspects of their reality. The intervention also aims at inviting patients to find words and develop meaningful stories by reflecting on their photographs. Assuming that the process of meaning making of illness experiences is an integral part of recovery, and that the role of nurses in assisting in this process is valued highly by patients themselves (Wilken, 2010), we wanted to investigate whether the photo-instrument is useful in reaching this aim and, if so, how the methodical structure of the intervention can render nurses a tool for delivering 'good care'.

Aim and research questions

This thesis deals with the question how photography can assist psychiatric patients in making meaning of their illness experiences to foster their recovery. It is assumed that the construction of illness experiences and the reconstruction of meaning through photo-stories is an essential part of the process of recovery. Departing from this general question and hypothesis we formulated four sub questions (one philosophical, two empirical and one concerning the methodical aspects of the intervention):

1. How can the process of meaning making be conceptualized in terms of hermeneutic phenomenology, as developed by the philosopher Paul Ricoeur?
2. How do psychiatric patients give meaning to their suffering with photo stories?
3. What is the therapeutic role of the photo-instrument (the specific nursing intervention with photography used in the study) in the context of recovery?
4. In what way do the methodical steps of the photo-instrument facilitate nurses to deliver good care in the context of mental health care?

The study starts with conceptualizing the process of meaning making through photography (question 1). For this aim we turn to the hermeneutic-phenomenological philosophy of Ricoeur. Hermeneutics studies the way in which people make meaning and phenomenology ties this to actual phenomena and existential problems. In our study we focus on two interrelated phenomena, namely the experience of suffering, and caring as an answer to suffering. The theoretical framework provides the concepts to understand the processes of meaning making in practice. We then investigate our nursing intervention, the so-called photo-instrument, which is grounded in the philosophy of Ricoeur. The essence of this intervention is that patients make photographs of their current lives and goals for the future. The meaning of the photographs is not given, but constructed by telling stories (which we call photo-stories) about the pictures and by interacting with fellow patients in a group, under guidance of a nurse. Some pictures are exhibited to share meanings with the larger social network. The intervention is targeted at psychiatric patients. In our study the intervention is applied in mental healthcare settings to empirically study how patients make sense of their suffering through photo-stories (question 2) and what therapeutic role the photo-stories play in the lives of the participating patients (question 3). Lastly we will study the methodical implications for nurses and other healthcare professionals (question 4). Although we start with theory and continue with practice, theory and practice are interwoven throughout this study.

In the next sections we will first have a closer look at our understanding of nursing and good care. Then we will describe how these are related to concepts of recovery, empowerment and health. We will show that meaning (re-)construction is central to the process of recovery. From there we will argue that storytelling is necessary for meaning (re-)construction of experiences of illness and recovery. We will link this again with nursing by describing how storytelling creates a relational narrative when nurses enter upon a dialogical interaction with patients. We will argue that this relational narrative has the potential of empowering patients. We will further focus on the meaning making process itself and on the role of aesthetic experience. The photo-instrument will then be described in more detail, since it facilitates this aesthetic experience in an empowering

way. The exposé on the photo-instrument will be followed by a closer look into the research that we have undertaken and on which this thesis is based. The introduction will end with an outline of the chapters of this thesis.

A hermeneutic-phenomenological perspective on nursing and good care

Nursing is a professional practice in which nurses give care to their patients. They for instance make observations of a patient's physical or mental condition and then decide what intervention is most fit to improve patient's health or make suffering bearable. This may be called technical professionality (Kunneman, 1996), focusing on technical proficiency and good craftsmanship. Technical proficiency can be experienced by patients as caring when it is done in a respectful and attentive way with an eye for the patient as a person who is part of a social system and who tries to give sense and meaning to his life. However it can also be experienced as non-caring when the nurse is hurried or performs the intervention as a job that needs to be done, almost irrespective of the person concerned. Nursing demands an attitude that is sometimes described as 'being present'(Benner, 1989; Baart, 2000): build a relationship with an open agenda, give full attention to the person without preconceived ideas and only then try to understand someone's needs and act upon this understanding. Nursing is a caring relationship requiring being involved with focussed attention and concern. A caring relationship presupposes that every patient is a unique person. Understanding that patients, just like nurses, have matters of concern and issues of significance to them, is essential to a caring relationship. This may be called normative professionality (Kunneman, 1996). Good care as a normative standard for nursing contains both forms of professionality. Taking care *of* a patient expresses itself in technical craftsmanship, but needs to be combined with caring *for* the patient, being focused on the person of the patient and his or her needs (Tronto, 1993).

Caring is the core mission of nursing, taking priority to more interventionist routines in which nurses help patients to cope with illness and disorders or to recover from them. Caring can be seen as flowing first and foremost from the nurses' response to the suffering of patients (Eriksson, 2006; Fredriksson & Eriksson, 2001). From a hermeneutic-phenomenological point of view suffering occurs when someone feels incapacitated to act as an agent (Ricoeur, 1992). The word patient suggests the opposite of agent. In the medical model the focus has always been on illness that necessitated professional expertise to be called in. It tends to confirm patients as patients, that is as passive recipients of care. This has called forth a counter movement that pleaded for enlarging

the possibilities of empowering patients and strengthening their agency. This move towards a more patient-centred care however may give way to a too narrow emphasis on rights and participation in civic roles and may ignore or neglect that people have become patients in the first place *because of* their vulnerability and lack of agency. Nursing, when basing itself on its essential *raison d'être*, namely being a professional response in the face of someone else's suffering, can not but take into account both aspects.

Recovery

The concept of 'recovery' is often used to denote the struggle of psychiatric patients to live a life beyond the disease. Recognizing that complete cure from the mental disorder is often illusionary, patients strive for more agency and more direction in choices in life in order to realize a better quality of life. Through consumer councils and groups, recovery was promoted as an important issue on the agenda of mental health professionals. In the United States, Patricia Deegan's (1996) personal account of her own recovery has played an important role in raising awareness of the possibility of recovery. In the Netherlands, the experiential researcher Wilma Boevink (2007) introduced the HEE-concept (Herstel, Ervaringsdeskundigheid and Empowerment).

Anthony (1993) identifies recovery as "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness."

Anthony shows that recovery is intrinsically bound up with how one experiences the social world and one's role in it. The process of recovery is always situated in one's life world. The life world is reality as experienced by the subject: how disease is perceived as being embedded in routines of daily life and life circumstances, enacted and responded to by patients themselves and by others. The concept derives its poignancy from its opposition to 'system world', a concept coined by Habermas (1987) and denoting the whole complex of roles and functions of individuals in societal contexts. System world refers to the perspective of institutions, structures and functions of the system (society seen from a systems-theoretical approach) in a structural sense (Kemmis & McTaggart, 2000), whereas the concept of life world emphasizes that a life is lived within certain local settings (family, professional life, etc.). In the life-world, well-being is an embodied experiential process that usually is bound up with all aspects of every day life (Benner, 2000). Our well-being also depends on a development through time (the aspect of the life story) that finds expression in looking back on things from the past as well as looking forward to possibilities available in the future. Recovery implies enlargement of the

possibilities within the life story to act upon these evaluations and estimations. Going through a process of recovery, a patient finds out that his life is not completely dominated by illness, but that alternative meanings are possible which are associated with values, wishes and reminiscences from a life beyond being a patient. In this way patients may feel less infringed by illness and experience more space to breathe and more openness to live a valued life. The mission of nursing can be described as having a role in the prevention or cure of diseases and disorders and, where that is not possible, helping patients to cope with the consequences in daily life (RVZ, 1998). Recovery-oriented nursing also assists patients in evaluating experiences with illness and health in the context of their life story, creating more openness for new meanings and contributing to the development of possible actions based on strengths while being aware of vulnerabilities.

In order to assist patients in evaluating and developing actions, nurses need to listen carefully to the stories that patients tell them. Narratives told by patients can be seen as a way 'to explain and contextualize interrupted lives and changing relationships with the social world' (Freeman, 2001; Bruner 1990; Bury, 1982; Charmaz, 1991, Riessman, 2003; Williams, 1984). Understanding them requires a suspension of preconceived ideas and diagnoses and a tuning to the patient in a subject-subject relationship. The nurse recognizes the patient as a subject to which he or she relates as a subject (Gadow, 1999). Nurses can facilitate patients to show and communicate emotional-laden and/or diffuse feelings, primarily in bodily expressions. Pain and sorrow may induce tears and feelings of grief, and sometimes be put into words. Suffering entails embodied and experiential knowing. People express their suffering in a bodily way. For instance sorrow 'speaks' from someone's looks and repression can be 'written' in someone's posture and glance. The embodied message of this experiential knowledge and feelings may be read. An experienced nurse can interpret these embodied messages where patients sometimes are not yet able to voice them in language. The verbalization by the nurse may help a patient to understand sometimes diffuse and confusing thoughts and feelings. The experience of being understood in the deepest of feelings can set someone free from oppressing anxiety and open up new perspectives and give new energy (Benner, 2000; Wiltshire, 1995). We consider this as forms of empowerment. We will go into this concept in more detail in the following section.

Empowerment

The concept of empowerment encompasses two aspects. It acknowledges that patients are vulnerable and lack agency, but it strives for ameliorating this and create better conditions for more patient participation. Empowerment is an important 'root metaphor' for health promotion. It is the basis of the Ottawa Charter for health promotion (WHO, 1986) that defines health promotion as "the process of enabling people to exert control over the determinants of health and thereby improve their health". Introduced in the Netherlands in the nineties of the last century it rapidly became a popular concept that was used in many programmes for health promotion and prevention (Jacobs, Braakman & Houweling, 2005). Empowerment can be conceived as both a process and an outcome. As an outcome it relates to the experience of control and having access to sources and services (for instance health services). As a process it relates to increasing participation of people in decision making settings. It also relates to a psychological dimension of perceived control, self-efficacy, motivation to control and perceived competence. On a personal level empowerment encompasses three components (Jacobs et al, 2005):

1. Beliefs that one can make a difference and that one's actions can produce results.
2. A growing critical awareness of one's possibilities in the context of existing values and norms. Also a growing insight in what skills are needed to realize one's goals.
3. Community participation that builds on people's identification and bonding with their social networks or place of residence.

Empowerment can be regarded as a necessary condition for recovery. The role of nurses is to empower patients and thus to contribute to recovery. One may also say that empowerment leads to improved health, if one uses a broad definition of health.

From a hermeneutic-phenomenological perspective nursing defines health not as the absence of disease, but takes a broader perspective. This is conform the definition the World Health organization (WHO) that formulates health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (WHO, 2003). Health is seen as wellness and the capacity to use one's freedom and potentials to relate to the world around oneself, establish and maintain satisfactory contacts with other people and in doing so being able to express one's individuality and creativity (Benner, 1989; Dahlberg, Todres & Galvin, 2008; O'Connor, 1993; Travelbee, 1966). Illness is different from disease and disorders. Illness is a condition in which existential possibilities to act as an agent are broken off or are interrupted. When you are ill you are obstructed in engaging in meaningful relations with the world around you. In this existential view of illness we distinguish illness from disease, the latter being much

more functional impairments that can be medically assessed and diagnosed (see also Kleinman, 1998). Diseases can cause illness, but this is not necessarily the case. With a severe mental disorder one can still lead a meaningful and satisfactory life, although symptoms may make this very hard and even at times impossible. Looking upon illness and health in this way may be called a social-ecological approach (Labonte and Laverack, cited in Jacobs et al, 2005). Besides physiological and psychosocial factors it takes into account that there are social-cultural, structural and physical environmental conditions that matter. Striving for health and healthy life styles is broadened to encompass quality of life and the possibilities for directing one's life. Wallerstein who performed a meta-analysis of 4000 articles of which she reviewed 500 in depth, came to the conclusion that:

"Patient empowerment and family caregiver interventions have shown improved self-regulated disease management, use of health services and mental health. While not all studies measured individual empowerment outcomes, interventions with empowering characteristics, such as promotion of patient partnership and mastery over their condition, and use of group educational sessions facilitating a supportive environment and dialogue, have shown significant impact in improving health and quality of life in chronically ill patients" (Wallerstein, 2006, p.12).

Nursing departs from the patient's vulnerability and lack of agency, and aims at enlarging the control of people over the determinants of health, thereby improving their health. Illness as the opposite of health is considered here as a condition in which existential possibilities to act as an agent are broken off or are interrupted. When you are ill you are obstructed in engaging in meaningful relations with the world around you. However, functional impairments caused by diseases and disorders do not necessarily have as a consequence that people can not have a meaningful and satisfactory life. Nurses can empower patients to regain a meaningful and satisfactory life.

In the next section we will describe how meaningful relations with the world can be promoted by nurses when they develop a relational narrative with their patients. The role of story-telling in developing a relational narrative holds a central position. This is of great importance in the context of this thesis as we focus on processes of meaning making through story-telling with photographs.

Developing relational narratives through dialogic interaction

In modernity, individuality is seen as a valuable asset. It is associated with autonomy and considered to be a private domain of the ego that is strictly delimited from the outer world. Although autonomy is important, the fundamental way of experiencing ourselves is not monological, but dialogical. Persons experience their identity as the result of an ongoing discourse, a 'conversation' with no beginning or end. It is a conversation that goes on in someone's head between positions that one can take up, roles and different views which compete with each other to come to the foreground for expression (Hermans, 1995). It also reflects a continuous interaction with the external environment in which one tries to understand oneself and legitimize one's actions (McNamee & Gergen, 1992; Gergen, 1994; Nijhof, 2000; Polkinghorne, 1998). Through telling stories, a person defines her identity. Philosophers like Ricoeur (1991) and MacIntyre (2001) claim that men need stories to motivate their actions and present themselves to others. This is the performative function of stories.

Story-telling presupposes an audience of listeners who hear the stories and 'receive' them. How a story is told is the outcome of the dynamics of the interactional process (Boeckhorst, 2001; Harden, 2000), which may vary with different audiences. Telling one's story in a hospital setting to nurses is different from telling what has happened to one's best friends. Responses within the same audience may also vary widely. For instance, nurses may listen to a story of a patient and hear only those details that are relevant for them to make a problem list and plan nursing goals (Abma, 1998). Or they may listen to patients in a responsive way without having their own agenda heavily imposed on the conversation. Depending on how nurses respond, patients may or may not adapt their storytelling, often without realizing that they do so, to fit in with a professionalized version of their story. Nurses and patients are both agents who construct meanings from what is been told in an exchange of affirmation, contradiction and silence. Sometimes both parties arrive at a shared understanding of a 'true story' that can be taken as a point of departure for further actions to engage in (Gadow, 1999; Sakalys, 2000). Such a story is a relational narrative (Abma, 2005). The importance of arriving at a shared understanding through dialogue lies in the widening of horizons where one otherwise would risk sticking to one's own, often narrower points of view, but also in the experience of sharing. The acceptance of a common ground and perspective in a relational narrative creates a bond between the partners that translates itself in commitment to common goals.

A relational narrative may give room for a discussion of dominant cultural narratives, e.g. our views on diseases and disorders that are entrenched within medical praxis. Notions of disease tend to overgrow other alternative interpretations of someone's trouble or problems sometimes to the degree that someone identifies himself with a disorder. Following Habermas, this can be called the colonization of the life world by the system world (Kunneman 1983/1984). A sick person runs the risk of becoming his sickness and having his identity determined by his medical diagnosis, instead of considering this as a possible interpretation of part of his life trajectory (Boeckhorst, 2001; Roberts, 2000). Since audiences influence the story, nurses' responses can have great relevance. For instance, nurses who respond with empathy to a patient telling about hearing voices may influence how the patient looks upon his complaints: not as something that marks him as a schizophrenic, thus setting him apart from the world of 'normal' people but as having more extreme sensations in a range of mental activities that all people have. This is the therapeutic potential (e.g. Clark & Standard, 1997) of narratives in a dialogical approach. Bakhtin (1981) claimed that in story-telling meaning is expressed and that this expression feeds back on the interpretation of meaning, which in its turn influences patterns of thinking of which these meanings are part of. Bakhtin's dialogical approach can also be applied to nursing praxis (Bowers & Moore, 1997). Bakhtin assumed that in social interaction there is a continuous interplay and reciprocity between consciousness and meaning giving. The social and psychological entities that arise from the interactions between the self and the others can be characterized as a dialogue with an open end. Structures, concepts and entities are constantly adapted and transformed in local contexts. When used with story-telling in conversation they reflect momentary states in a fluid movement. There are, however, strong stable constant elements in identity-formation, as certain social scientists (Geertz, 1988; Bruner, 1990) argue, opposing the more radical view of some social-constructionist psychologists (e.g. McNamee & Gergen, 1992; Gergen, 1994) that all meaning is constructed within the situated context. There is a complex interaction between the constancy and the adaptability within identity-formation. This is also mirrored in the phenomenological-hermeneutic tradition which is the background of this thesis.

Mimesis as the core of meaning making

Hermeneutic phenomenology originates from the writings of Heidegger, Gadamer and Ricoeur. Heidegger (1998) emphasized that meanings and knowledge are expressed and transferred through embeddedness in cultural and social contexts. Gadamer (1960/1990) expanded this insight to an understanding of the formation of experience.

He assumed that the experience of the particularity is enriched by merging with general meanings and forms of consciousness that are embedded in traditions and cultural practices (Wirkungsgeschichte). One of these cultural practices, the experience of art, served for him as a model for hermeneutic experience per se. Gadamer claimed that our perception is never purely given in our senses, but is always informed by a pre-understanding of meanings. The aesthetic experience of a work of art becomes a true experience (Erfahrung) when it changes the person who experiences it. In this dialectical process, a generic meaning is transformed into an individual understanding. This is for instance what actors do when they perform a play. They appropriate and integrate their understanding of a character they play into their own body of experience. Thus they are able to put a character on stage that convinces us as spectators. The elements interpretation, translation and expression recur in other forms of hermeneutic experience as well (Hagedorn, 1996). Ricoeur (1984) used the concept of mimesis to describe how meaning in text becomes interpreted through metaphorical transformation. 'Text' with Ricoeur (1991) could be anything from verbal text to situations, artistic expressions and actions. Mimesis concerns the process of meaning (re)construction, involving stages of communication, interpretation and in the end integration of the text in the life world of the person who 'receives' the text. Beside a phenomenological analysis of the process of meaning making and text-interpretation, Ricoeur also left us a broader philosophical framework in which agency and suffering play an important role. For these two reasons, we have chosen the work of Ricoeur as the background against which we have situated our research into the photo-instrument.

The aesthetics of meaning making

Aesthetic experience can be regarded as an integral aspect of the phenomenology of suffering. This was exemplified by the poem of Jan Arends, expressing essential aspects of the illness experience. On the one hand, the poem shows what diseases and disorders mean in terms of suffering, problematizing life as a work of freedom. On the other hand it implies the return of an ability to connect with values, beauty and a carefree life, as it refers to the sublime (Radley, 1999). By highlighting this aesthetic aspect, we want to prevent abusing aesthetics by suggesting that suffering is a thing of beauty. We want to emphasize that, while recognizing the suffering, one can still appreciate the aesthetic moment, found in fragments of an experience that stand out from the background. Rather than qualifying fragments of experience as 'beautiful' or 'horrible', the aesthetic moment should be linked up with the act of exemplifying. The ordinary chain of events that corresponds with suffering and the details of everyday living must be exemplified

in particular moments in time that stick out from the stream of flowing time and the mundane routine (see also Walter Benjamin, 1979). In the chasm of the mundane and the particular an experience is forged that invites the sufferer to further reflection and in the end to re-establish a sense of direction and coherence (Radley, 1999). This regained sense of direction and coherence requires expression. The articulation of an aesthetic quality transcends it from a mere metaphor or an idea to a lived truth to be recognized by others (Frank, 2002).

The photo-instrument

As emphasized in our previous discussion of hermeneutics, a relational narrative, told by patients with the assistance of nurses, not only interprets suffering and recovery, but also expresses and realizes them in interaction with others. The photo-instrument integrates an aesthetic experience into the narrative dialogue between patients and nurses. The photo-instrument is a 'text' in the sense of Ricoeur, encompassing communication, interpretation and integration of meaning into the life world. The aim of our research project was to investigate what this use of photography can contribute to an agenda of narrative-based nursing focusing on how patients give meaning to matters of health and illness.

The photo-instrument is a protocol led nursing intervention in mental health care using the medium of photography. It was developed by the author of this thesis as part of his education as a nurse specialist in mental health. A protocol was written that formed the guideline for an action research in which the author collaborated with 3 other nurse researchers. In 2002 this action research took place on 5 sites in 3 mental health institutes with a total of 24 patients. The action research resulted in confirmation that the intervention was feasible within the context of mental health care. Fine-tuning took place at intermediary stages until a satisfactory result was reached (Bouhuis, Middelhoven, Schoneveld & Sitvast, 2002).

The dosed and structured design of the intervention makes it specially suited for the target population of patients with a mental health disorder. The protocol contains several steps which aim at helping patients to give meaning to their experience by taking photos of their life world, and discuss them with others (see the appendix for the manual with detailed steps and instructions). The intervention contains individual assignments and group meetings. At the start the participating patients receive a disposable camera. The first assignment focuses on making photos of what patients value as important in their lives here and now. The photos are the basic material for further exploration of subjective experiences of the patients. In a number of group sessions facilitated by two health workers (e.g. a nurse and an occupational therapist) photographs and stories about them

are selected for an exhibition aiming at a wider public. Every participant presents his or her own photo-story. After the exhibition the cycle is repeated with a new assignment. The assignment now challenges patients to imagine who they want to be or what they would want to achieve in a year from now and what obstacles and chances they will meet on the route. This round of group sessions also ends with an exhibition of photographs and text that tells the story of every individual participant.

Actions	**Goals/Aims**
First Round	
Instruction in the use of the camera Explication of the assignment: focus on here and now And making first photographs	Containment
⇩	
Opportunity for making photographs in between sessions, with assistance on call	Connection with life world
⇩	
Photographs are pasted to worksheets Group of photographs are tagged with short notes describing contents	First grouping and sorting Attribution of meaning
⇩	
Participants are interviewed about their tags Group members are invited to respond to each other	Photo-elicitation Dialogue and reflection
⇩	
Participants select photographs And prioritize photographs for further reflection	Selection and prioritizing
⇩	
Participants are interviewed about their choices Group facilitator takes notes of participants' reflection Group members are invited to respond to each other	Photo-elicitation Dialogue and reflection
⇩	
Group facilitator return printed notes to participants Participants correct or supplement them if necessary Participants add text lines from corrected notes to selected photographs	Further reflection and meaning making
⇩	
Participants select three pictures for an exhibition Dialogue about aspects participants want to reveal about themselves and discussion about possible effects on private life	Selection for representation Dialogue and reflection
⇩	
Preparations for an photo-exhibition (writing invitation cards, producing announcements, etc.) Sharing tasks among participants	Sharing and commitment
⇩	
The Photo-exhibition opening night Participants act as hosts	Representation

Actions	Goals/Aims
Second Round	
Explication of the assignment: photograph a wish you would want to fulfil and also what it takes to do so Brainstorming about how to picture a wish Participants are invited to help each other	Containment
⇩	
Opportunity for making photographs in between sessions, with assistance on call	Connection with life world
⇩	
Photographs are pasted to worksheets in 4 prescribed groups: 1 a wish or goal; 2 necessary strengths; 3 obstacles; 4 sources of support Group of photographs are tagged with short notes describing contents	First grouping and sorting Attribution of meaning
⇩	
Participants are interviewed about their tags Group members are invited to respond to each other	Photo-elicitation Dialogue and reflection
⇩	
Participants select photographs And prioritize photographs for further reflection	Selection and prioritizing
⇩	
Participants are interviewed about their choices Group facilitator takes notes of participants' reflection Group members are invited to respond to each other	Photo-elicitation Dialogue and reflection
⇩	
Group facilitator return printed notes to participants Participants correct or supplement them if necessary Participants add text lines from corrected notes to selected photographs	Further reflection and meaning making
⇩	
Participants select 3 or 4 pictures for an exhibition Dialogue about aspects participants want to reveal about themselves and discussion about possible effects on private life	Selection for representation Dialogue and reflection
Writing an introductory note to go with the photographs in which participants tell how the pictured wish challenges them to act upon	Connection with life world
⇩	
Preparations for an photo-exhibition (writing invitation cards, producing announcements, etc.) Sharing tasks among participants	Sharing and commitment
⇩	
The Photo-exhibition opening night Participants act as hosts	Representation

Figure 1: Flow chart photo-instrument

Research methods

Study design

In this study we used a qualitative approach, combining various qualitative research methods. In one of the studies we combined qualitative and quantitative methods.

The overall approach of the study is that of 'focused ethnography' (Morse & Field, 1996), entailing a multiple case design in which each participant in the photo workshop represents a case. As common within qualitative research the data analysis was an integrated activity, steering the further data collection. All the data and analyses of a case added up to form a 'composite research case' (see chapter 4).

The ethnographic approach was chosen because we wanted to explore the experiences of a group of people going through a process of recovery from a psychiatric disorder while being participant in a photo group. This equals *the cultural group* in classical ethnography. Participants may not be part of the same culture (in a broad sense), but they do share behavioral norms and a common language emanating from experiencing a common illness. The *site* of the research in focused ethnography is often a treatment site: in this case the location of the residential home or the day treatment ward where the sessions of the photo group are organised. *Participant observations* concern the interaction within the photo group, the exchange of experiences with group facilitators and with other participants. The *topic* is the process of taking and selecting photographs for further comment, formulating text that matches the photographs and then using the photo stories for making a representation of oneself. Beside participant observation interviews were held with participants, group facilitators and mentor nurses. This implies a more limited focus on particular events (meaning construction to matters of health and illness) and moments in time (the sessions of the photo group) than is usual in classical ethnography (Van Manen, 1988).

Participants

The participants in our study were consumers of mental health care services who took part in photo groups. Sixteen photo groups were organized by the first author in the years 2005-2009 within five institutes of mental health care and various settings of psychiatric services: ambulatory as well as clinical, all situated in the eastern provinces of the Netherlands. Settings varied from a (medium-) long stay treatment ward in a psychiatric hospital, to a daytime treatment centre, and three sheltered homes. The target population varied from the elderly to adolescents who had gone though a psychosis. Inclusion criterion was that patients were not in an acute crisis phase and were not troubled by acute symptoms. Sampling was organized on a convenience basis. All participants of

photo groups were approached (face-to-face) in an informed consent procedure. Extra provisions were made in case photographs would be selected for publication in order to safeguard matters of privacy. The relationship with the researcher was established prior to study commencement. The researcher had no treatment or caring relation with the patients. Candidate participants were informed about reasons for doing the research, namely that evaluating and optimizing the photo-instrument made it necessary to do scientific research into its operation. 74 Participants consented to participate in the study. They reflected an average sample of patient population when considering age, residence status (inpatients-outpatients) and diagnosis cluster (see chapter 6).

Research team and reflexivity

The first author in this thesis conducted the actual research. He participated in nine of the sixteen photo-groups, collected photo stories and evaluation forms, conducted interviews and had the Sickness Impact Profile questionnaire filled out by all participants. He also took care of instructing the group facilitators and coached them in pilot runs of the photo groups. The analysis of data and report writing was done by the first author though aided through peer review by prof. dr. Tineke Abma and prof. dr. Guy Widdershoven, both working at VU University Medical Center, Department of Medical Humanities, Amsterdam.

The first author holds a MA-degree in history, was educated as a nurse specialist and has worked as a researcher at a mental health institute for the last 9 years. Interviewing clients in ongoing research that supports quality of care is part of his job. The reason why he is interested in the research topic goes back on his fascination with oral history and the history of mentality: how do people think and feel the way they do and how do patterns in thinking and feeling change over time. The assumption is that these changes are reflected in the stories that people tell about themselves. As a nurse specialist he devised the photo-instrument as a tool for nurses to tune in to the stories that patients tell about their lives. He expected the photo-instrument would contribute to a narrative-based nursing that actively uses the potential of photo stories for an agenda of change and empowerment. Undoubtedly these expectations have also biased him for an interpretation of data that pointed in this direction. Care has been taken to limit such bias via the application of several quality procedures which will be discussed in a meantime. Being transparent and critically reflecting on one's agenda and filters which may color the analysis is one of those measures, and is requested as an item to report (Tong et al, 2007).

Data collection

We used a combination of methods to obtain a more complete picture of the reality of photo groups in this study. Interviews were held with patients to take an inventory of personal experiences and opinions about sickness and suffering. Photographs and the stories participants had told about them were collected to see what meanings participants gave to their illness and how they suffer from it. Participant observations were done during sessions of the photo group to gain an insight into group dynamics and communication patterns between participants and group facilitators. Besides aspects of communication we also focused on other aspects of performance as for instance: motivation, initiative, etc. This overall picture was further refined by more structured methods as observations by group facilitators, the use of evaluation forms at the finish of photo group sessions, evaluation interviews and the use of a questionnaire. Group facilitators filled out standard observation items concerning group processes, communication and performance (table 1). With evaluation forms we took stock of how patients felt and thought about their participation in the photo group retrospectively. Participants were asked to fill out a questionnaire, the Sickness Impact Profile (SIP), that gave us more details on the perception of the influence of illness on daily functioning and how this may have changed because of participation in the intervention. This questionnaire was also used to differentiate between respondents who perceived less impact of sickness on their daily lives after following a photo group from those who did not and those who remained the same. A sample of these three groups was used to organise in-depth interviews among patients and mentor nurses. These interviews differed from interviews we held at the conclusion of a run of the intervention as part of an evaluation trajectory. In these latter interviews the focus was much more on how satisfied participants were with the help the procedures of the photo group had given them to tell their story. The in-depth interviews, that had duration of one hour, were reserved for the exploration of the perception of change and stability on a deeper introspective level.

Combining qualitative and quantitative methods we made use of a mixed methods approach, in which we aimed not only at triangulation of data but also at complementing the interpretation of qualitative data with quantitative data and vice versa.

The body of collected data thus consisted of texts (photo stories, interviews and evaluation forms), observations and answer items from the SIP-questionnaire (table 1). Photo stories are considered to be 'texts' that consist of photographs and accompanying text in one whole. Photos are 'text' in the sense that the image does not speak for itself, but requires interpretation to unravel its meaning. The story accompanying each photo reflects the meaning the participant endows to the image, and has been investigated by the participant observation of the photo groups as well as via interviews with participants.

In this way cases of persons were constructed on the basis of the trajectory that participants passed through while participating in the photo group. Within the group of 74 participants data of 47 participants in nine photo groups were collected more extensively to construct case stories that formed the main body of our study (table 1). Within this sub dataset there was a drop-out in 5 cases that occurred while the intervention was going on, resulting in 42 instead of 47 case trajectories. This particular drop-out was due to dismissal from the care program before the series of photo group sessions were completed.
Dropout from the overall study (N=74) occurred mainly at T3 (six months after completion of the intervention) and in general did not reflect dropout from the intervention. Drop-out at that time (N=26) can be ascribed to reduced study adherence due to the lapse of time and loss of contact.

Setting of data collection and other details
Photo stories were collected from participants in the study at the end of photo group sessions in the place where these sessions were organized. Evaluation interviews were organized in the same location (usually the locale of occupational therapists or a quiet room in the sheltered home). The in-depth interviews with participants were held at private rooms of the participants within a residential home. An interview guide was not used as all interviews were done by one and the same researcher (the first author). A topic list was developed on the basis of the overall framework of the SIP-questionnaire and our need to have respondents reflect diachronically on changes in their perspectives of how they function right now and how that will be in the future. Topics therefore were: have things changed compared with when they participated in the photo group; what do they think of their level of functioning at this moment; what are their aspirations and hope for the future? Interviews with mentor nurses were held at their offices. The topics of these interviews were the same as those in the interviews with participants but then from the point of view how the mentor nurse looks upon them from his knowledge and experience of the participant in a treatment context. Besides the participants and the researcher no one else was present during these interviews. There were no interruptions during the interviews. The interviews were audio-taped and transcribed verbatim. Transcripts were returned to participants for comments and/or correction. Comments were added to the transcript in an addendum. Corrections were integrated in the text. Besides this member check of basic transcripts there was a member check of interpretations, but this was done as an integral part of the composite research case (see below). There were no so-called repeat interviews. Field notes were made during interviews but only on a limited scale. The duration of interviews depended on the responsiveness of the persons interviewed but varied between one hour and one hour and a half. During participant observation the researcher did not actively involve himself in the proceedings of the intervention.

He acted unobtrusively and in a natural way. Field notes were made, but again unobtrusively. Evaluation forms were filled out as part of the intervention's proceedings without explicit reference to research purposes. Permission to use evaluation forms was obtained afterwards and on an individual basis.

Table 1: Data collection

Method of data collection	source	Number	Type of information	Time of data collection
Gathering of texts generated not for research purposes but emanating from intervention procedures	text	42	Photo stories, containing the perspective of participants on their mental illness, their suffering and recovery	During sessions of nine photo groups 2005-2008
Participant observation	Field notes	42 cases, each case differentiated in 8-16 sessions	Group dynamics Communication patterns Performance as narrator Psycho-social aspects	During sessions of nine photo groups 2005-2008
Observation by group facilitators	Structured forms with predefined closed scoring items	42 cases, each case differentiated in 8-16 sessions	o Degree of initiative taken by participants o Responsiveness to other group members o How participants responded to feedback o Originality or imitation of story plots among participants o Degree of openness or reticence o Motivation o Feelings of shame o Psychological aspects: concentration, anxiety, mood, psychotic symptoms	During sessions of nine photo groups 2005-2008
Evaluation	Structured forms with predefined closed questions	42 cases	Participants' experiences, with the steps and procedures of the intervention and how these facilitated the telling of a photo story	During closing sessions of nine photo groups 2005-2008
Evaluation	Semi-structured interviews	8 participants 4 group facilitators	o Participants'' experiences from evaluation forms further explored and amplified / explained o Experiences of group facilitators, concerning their impressions of performances of individual participants ; fidelity with intervention protocol	In a post-intervention meeting
In-depth interviews	Semi-structured interviews	8 participants 8 mentor nurses	Participants'' views on (changes in) their level of functioning	9 months after the finish of a photo group
Questionnaire	The Sickness Impact Profile (SIP) Questionnaire	74	Structured forms with predefined closed statements with which one can agree or disagree. Statements concern aspects of daily functioning in relation with health matters.	T1: at the start of a photo group T2: at the finish of a photo group T3: 6 months after the finish

Data analysis

We combined a hermeneutic analysis with a thematic content analysis and an ethnographic analysis of observational data in a multi-level framework. In a sub study this was complemented with a statistical analysis of data from the questionnaire on the perception of the impact of illness.

The hermeneutic analysis focussed on the photo-stories and considered photographs and accompanying text as one integrated body of text. As we consider the photo-stories as one body of text we analysed the images and words not separately, but as an integrated whole. It is assumed that there is a fluent transition from images into imagery and from there in story-telling (words). By themselves the studied photographs were multi-interpretable, but set in a story the picture(s) gained a specific meaning endowed to them by the owner of the photograph. The proverb goes that one picture is worth a thousand words. This may be so, but for the sake of signification pictures cannot do without words. Making meaning of the photographs is thus to be seen as a double-hermeneutic process. First the patient and owner of the photograph gives meaning to the image by telling a story about it. Next, the researcher interprets the photo in combination with the story (the photo-story) as an integrated whole. In hermeneutic understanding each detail is related to the whole and should fit into whole and the whole should cover all details to create a valid interpretation. To check the validity of the interpretation made by the researcher the analysis is presented to the owner of the photo-story (member check). Co-checking (researchers comparing their interpretations) is the procedure to enhance the reliability of the analysis.

The photo-stories were analysed to determine how the text was constructed from a narratological perspective in terms of plot development, perspective and role identification. We also looked into the social-semiotic aspect, that is how the text was devised as a message *referring* to a reality (*content*) of living with a mental illness within the *context* of group sessions in a mental health care setting. With a social-semiotic analysis we unravelled the way how photographs as a *seme* or sign refer to an existing reality, but also how they become the vehicle for bringing across to a public the lived experience associated with an external reality the photographs refer to. For both the hermeneutic and social-semiotic analysis a conceptual grid of core components was used as a heuristic aid (summarized in table 2). The items for the hermeneutic analysis were derived from hermeneutic philosophy of Ricoeur in which emplotment and agency play an important role combined with the pragmatics of the psychiatric rehabilitation approach for aspects as 'biographical relevance' and 'goal readiness'. Overarching our decisions for selecting these items was a pre-understanding that the studied reality was one in which processes of identity making-expression-representation took place. The fact that pictures (photographs) mediated these processes made us opt for items that

are formulated in visual studies (e.g. Van Leeuwen, 2001). This complex analysis was integrated into a thematic content analysis based on comparisons within and across cases.

Next we analysed how the experienced reality was related to factual information about real life conditions. Participant observation of the photo groups helped to observe the condition of the client: their verbal and cognitive skills, communicational patterns and psychosocial wellbeing. In a limited number of cases additional interviews were conducted with clients after the intervention. This was done to assess how they viewed their participation in the photo group. Also interviews were held with the nurses leading the photo groups to hear their view on the wellbeing and improvements of the clients. Observation forms filled out by nurses who conducted the photo groups and evaluation forms filled out by participants further helped to compare the story of the client with factual data. In this way cases were constructed that enabled us to make a multi-level interpretation. The cross checking between data aimed not to invalidate the clients' photo story, but to discover discrepancies between the story and actual situation in real life. Finding out what the story covered up, made it possible to interpret why clients used facades used in their photo stories and how they were functional for the client. Analysis was further enriched by focusing on the self-perception of the impact of illness on functioning in daily life. A statistical computation with SPSS was performed on SIP-data to find possible changes in self-perception during the course of a photo group. In-depth interviews with clients and their mentor nurses) who represented different subgroups in this respect enabled us to explore differences and similarities in perception across clients. This was done with a thematic content analysis.

Quality procedures

Following a hermeneutic perspective we used the notion of "credibility" (Lincoln & Guba, 1985) to ensure the validity of our study. Procedures to ensure credibility included a member checking of interview texts and interpretations of the composite case with the research subjects.

In the member checking of the composite research case we asked participants to read our interpretation of what the images were about, what stories they were part of and whether there were layers of meaning that we assumed to be present in a specific photo-story. As the research case contained theoretical notions on suffering and facades sharing with participants was difficult and not always possible. We therefore rephrased interpretations in terms familiar to the participants.

Prolonged engagement and persistent observation of the photo group setting helped to identify patterns and habitual interactions, and to distinguish these from incidents. Data collection continued till the point of saturation was reached, meaning that there was

repetition and no new information was added. Triangulation of data was accomplished by different methods of data collection, for instance: in the interviews we discussed patients' outcomes of the SIP. Findings were then tested against what mentor nurses reported in parallel interviews. Trustworthy interpretations were further achieved through reflexivity in a re-iterant process of discussion between first, second and third author, peer review and theoretical sensitivity. In qualitative research external validity is not reached through statistical generalization, but via theoretical generalization. Theoretical generalization refers to the inductive and systematic development of a conceptual and aggregated framework which remains tied to the particularities of the context (time and place). Via thick descriptions (rich descriptions with meaning and context) readers may generalize findings from the studied context to another setting.

Table 2: Frameworks of analysis

- **Hermeneutic analysis of text:**
  - -on the level of individual stories: 42 photo stories
    - Items that we focussed on were:
      1. plot development
      2. perspective
      3. role identification/agency
      4. how the participants use the collective repertoire of metaphors, sayings, popular wisdoms to make sense of their lives.
      5. biographical relevance
      6. goal readiness
  - -identification of themes in and between cases
  - -social-semiotic aspects of the photo's:
    - Contents: how 'images' are used in stories, e.g.: what 's been depicted in the photograph; interior or exterior; nature vs. humans; use of attributes; setting (e.g. hospital vs. domestic)
    - Referents: relation with reality, e.g.: to what degree do images carry symbolical connotations?
    - Context: at what public do the stories aim and how is the 'message' tuned to 'receivers'? (issues of credibility, representation and orientation)
- **Focussed ethnographic analysis of participant observation and observations of group facilitators**: observations were analyzed for patterns that match or possibly refute the hermeneutic analysis
- **Analysis of interviews:** inductive content analysis
- **Analysis of quantitative data from SIP-questionnaire:** statistical analysis using SPSS, using non parametric technique (Mann-Whitney) to compare averages in groups

Outline of the book

The thesis starts with a philosophical analysis of the foundations of the photo-instrument (chapter 2). Here we present our conceptual framework, focusing on meaning making. The central concepts of mimesis and performance are related to empirical data to check their relevance for understanding actual processes of meaning making observed in reality. We do so by describing the process and steps patients make in a photo group to give meaning to their illness experiences. These data are related to the theoretical framework. By tying our central concepts mimesis of performance to the empirical data we come to an answer to our first research question, thus laying a foundation for further empirical investigation of how the photo-instrument assists patients in making meaning of experiences of illness and recovery. Chapter 2 provides an answer to sub question 1.

Subsequently, we look into practice to see how patients use their photo-stories to make and express meaning of experiences around illness and recovery in order to answer sub question 2. In line with our central research question, namely finding out empirically what a practical intervention with photography can do in this respect, we adopt a phenomenological stance focusing on suffering and caring as answer to suffering. This leads us to supplement and infuse theoretical concepts with observations from practice, in this way enriching theory. This interplay between theory and empirical data is a strain that runs throughout all chapters, but is most prominent in chapter 3. In chapter 3 we tie the question of meaning making to the functionality of photo-stories. We investigate how photo-stories help patients to overcome or transcend their suffering..

In chapter 4 and 5 we focus on the therapeutic role of the photo-instrument in order to answer sub question 3. As we consider in chapter 3 the intra-psychic functionality of photo-stories, in chapter 4 we focus on the interpersonal aspects, which we formulated in terms of representation. Through intermediary concepts (‘face’ and ‘voice’) we connect the grand theory of representation with the reality of patients as we encountered in the praxis of the photo-instrument. From these in-between levels of conceptualisation we found a nexus in moral rehabilitation. This concept connects professional activity (rehabilitation) and therapeutic effects (moral learning). In this way the philosophical and hermeneutic tenor of the photo-instrument comes to earth and will be more readily translated in concrete methodical actions (which will be the purport of chapter 6).

In chapter 5 we focus on how participation in a photo group influences the perception of the impact of illness on one’s functioning in every-day life. We investigate how patients perceive their functioning in daily life and what anticipations they entertain on the

subject. It is here that the therapeutic role of the photo-instrument finds expression in its most mundane form as part of routines of every day life. Where in earlier chapters meaning making of experiences of illness and recovery was set in sometimes highly-flung ambitions we now reflect on issues that are more down-to-earth. As a matter of fact much of the support nurses give to patients will be in this field. Through describing the views of both patients and nurses we thus connect with the more practical domains of psychiatric nursing: helping patients to cope with the consequences of severe mental disorders in daily life.

In chapter 6 we shift the perspective from the patient to the nurse, reflecting on the methodical aspects of the photo-instrument as a nursing intervention in order to answer sub question 4. We identify the actions care professionals, e.g. nurses may take in facilitating patients to present their story in a meaningful way. We present these steps as operationalisations of two central concepts that we deduced from the theoretical framework that underlies hermeneutic photography: mimesis and performance. We also discuss the contribution of hermeneutic photography to the professional agenda of empowerment and recovery-oriented rehabilitation.

We have come full circle now through the steps of conceptualizing meaning making, investigating what it means to patients involved in meaning making (intra- en interpersonal process), describing the concrete effects that touch on issues in which nurses often support patients, and finally elaborating the methodical aspects of how nurses can use the photo-instrument as an intervention to facilitate recovery.

In the last chapter we summarize our findings and evaluate them in the light of our initial research question, showing what contribution photography can make to nursing.

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